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ABSTRACT

The physically disabled need to be assimilated into the mainstream of society, thereby enabling them to reject the environmental forces that have traditionally kept them psychologically isolated. Although rehabilitation centers may be the right places for the severely disabled to gain information that can augment that assimilation, they project a dependency for the disabled because they do not reflect the real world's physical environment. This paradox causes many disabled persons and their families to resist radical change and often locks the disabled into an isolating or closed system. The Rehabilitation Act of 1973 offers alternative opportunities for the disabled to reframe their systems through the elimination of architectural barriers and the provision of transitional housing. The disabled must choose to live in open or assimilating systems rather than in closed or isolating ones, to build symmetrical relationships in which two people interchange the same type of behavior, and to bring their decision making abilities rather than their dependency to their relationships. (AEA)

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THE WORLD OF THE DISABLED:

FROM ISOLATION TO ASSIMILATION

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The World of the Disabled:
From Isolation to Assimilation
Kenneth F. Sweet

When I was 24, the farthest thing from my mind was sitting in this wheelchair. Look around you. There is someone sitting beside you, behind you, in front of you, or near you who is going to be disabled. The future looks brighter for the largest minority group in the world. Over 50 million disabled individuals live in the United States and 500 million world wide. It is the one minority group that knows no sex, race, nationality, or color. A disability can evolve in a few seconds through an accident or gradually by old age or an illness.

One of the major reasons for the brighter future for disabled individuals is because they no longer live in isolation. Disabled persons are now assimilating themselves into the mainstream of society. "Disabled people are no longer going to lay back and not take action themselves."[1] For many years the disabled people had little to say concerning their lives. Physical isolation was a common practice either by placing the disabled person in a rest home or in the back bedroom of the family home. This practice created psychological isolation far more damaging than the initial act itself. From this psychological isolation evolves dependency and poor interactional systems. The disabled person interacts with his/her environment, but out of this environment is a movement towards a closing system. This interactional system closes because the disabled individual interacts with the same set of people and exhibits the same routine day after day with little change.

This psychological isolation may not allow the disabled individual to become a fully functional member of another subsystem. The behavior of the

able bodies community would often isolate the disabled person from interacting in that environment. For example, the disabled person may go with his family to a restaurant, a completely open system, and the waitress may interact with such comments as, "Would he like to have any dessert?" or "His wheelchair is sticking out in the aisle."

Interaction can be considered as a system, and the general theory of systems gives valuable insight into the nature of interactional systems.[2] In defining a system as "a set of objects together with relationships between the objects and between their attributes,"[3] in which objects (human individuals) are the components or parts of the system, attributes (communication behavior) are the properties of the objects, and relationships (persons communicating with other persons) "tie the system together."[4] Interactional systems shall be two or more communicators in the process of, or at the level of, defining the nature of their relationship.[5] For a given system, the environment is the set of all communicators, a change in whose communication behaviors affect the system and also those communicators whose communication behavior is changed by the behavior of the system.[6] When a system is closing, as in many cases of isolation, there is no import or export of energies in any of its forms such as information. In the case of an open system, that of assimilation of the disabled individual, there is an exchange of energies or information with their environments. A system can be classified as "open" for the disabled when it is "goal oriented, maintains certain rules or principles, has a certain order or method for operation, has a tendency to perpetuate itself, and has essential components that are related, interdependent, and interactive."[7] An open system fosters positive change and growth. The long-term goal generally remains constant, but the short-term goals are modified at intervals to reflect

intentional change. It allows for new information since it accepts the fact that it does not have all of the "answers." An open system continually evolves as this new information is assimilated and becomes part of the living system. The system's power to function arises from all of its member components.[8] A continued effort to update rehabilitation/medical, physical, occupational, and educational programs are essential in an opening system (assimilation).

For the severely disabled, the rehabilitation center is the right place to gain information to foster positive change and growth for the assimilation into mainstream society. The disabled needs company and counsel with people with similar injuries to themselves. The rehabilitation center is more innovative and creative than general hospitals, rest homes, and other medical institutions that do not relate to the specific disability in question. The information is gained from peer counseling that produces much of the creativity and innovation. The sheer quantity of information, the multitude of coping ideas and solutions, and the ease of communication when all present have similar concerns are truly enlightening. These people are, by far, the best advisors and the best access to information. The rehabilitation center allows for the gathering of like individuals to share information and the exchanging of ideas.

Today's information about rehabilitation for the severely disabled is likely to become tomorrow's mistakes and errors. Tad Tanaka, a quadriplegic for 30 years, in discussing rehabilitation, remarked, "I think it should be remembered that things were pretty primitive all around. Education, rehabilitation, everything. When I compare the services available now with the services available then, there's a huge difference. So I had no opportunity, really, to do anything."[9] Thirty years ago there were no organizations (Centers for Independent Living, The National Spinal Cord Injury Foundation, Paralyzed Veterans

of America, Division of Vocational Rehabilitation, etc.) that had reliable information about severe paralysis. As long as rehabilitation programs update their information, there is an open system assimilating resources of valuable information. We must remember that time is an important factor in the successful readjustment to the mainstream of society. Tom Deniston sums it up best when he states, "I think the first thing a person oughta do is get out of that damn hospital environment, because it'll kill you...the more reliant you become, the thicker that umbilical cord becomes and suddenly you can't get out." Initially, the philosophy for spinal cord injury was, "Oh poor dear, he's not gonna live long. So let him live fast, love hard, die young and leave a beautiful memory."[10] With this notion or idea the disabled could get away with anything but didn't get far from the hospital. This philosophy develops isolation tendency and a closing system and would not allow the individual the opportunity to become part of another subsystem.

The information that needs to be considered continuously to determine whether you are headed for isolation (a closing system) or assimilation (an opening system) are:

> If all or most of your time is spent in your room, even after the acute phase has passed, or if you are moved only once daily for an hour in a physical therapy cubicle, you're in the wrong place.
>
> If you have the feeling you're being hidden, you're in the wrong place.
>
> If you're not being taught to become a genuine expert, the expert, on all aspects of your own health, you're in the wrong place.[11]

According to George Hohmann, a long-time paraplegic, "Keep active, keep trying things, and don't find the answer. Don't let someone tell you you're found the answer, because if you do, by God, it's gonna be an institution or it's gonna be a nursing home or it's gonna be invalidism in your own house."[12]

Even though a rehabilitation center is the right place for the severely

disabled, there evolves a paradox concerning dependency and independency. A paradox may be defined as a "contradiction that follows correct deductions from consistent premises." Today's consistent premises are likely to become tomorrow's errors or fallacies.[13] One of the more frequent forms in which paradox enters into the pragmatics of human communication in dealing with the disabled is through an injunction demanding a specific behavior, which by its very nature can only "be spontaneous."[14] The significant other, who is continually stating, "I want you to want to be more independent," is in fact, causing dependency. The more this behavior is willed, desired, and awaited for, the less likely it will occur. The paradox for the disabled person is in the achievement of naturalness of spontaneity, which realities of their physical difficulties places them in an unattainable position. This brings on depression, self-hatred, and lack of self-confidence.

Rehabilitation centers bring out this paradox for the disabled. The rehabilitation center, with all of its wide doors, uncarpeted hallways, accessible showers and toilets, automatic doors, and adjustable beds, projects dependency for the disabled while the professional staff and others are saying, "be independent." The rehabilitation center is often not a reflection of the physical reality of the real world. This is why, in many instances, the disabled comes back to the rehabilitation center with some medical problem (such as, pressure sores, urinary track infections, contractors, etc.). Barry Corbet, a paraplegic, in discussing rehabilitation suggests that "Basic rehabilitation is a drag. It only teaches what you learn in the first four years of your life--mobility, personal hygiene, avoidance of hazards, muscle development," etc.[15] The paradox in Corbet's thinking is in the following statement: "The best thing going for it is that not doing it is much worse than doing it."[16]

The paradox of disability has such a contradictory effect that many disabled individuals and their significant others are unwilling to accept radical change. When change does occur, the process that creates the change takes longer, because decisions are based on practicality, economics, common sense, and red tape from administration. The severely disabled individual, who wants to become part of mainstream society and become educated, get a job, etc. which will lead to independency, becomes dependent on agencies or organizations that are part of the system. Here is this quadriplegic who has been isolated in some remote area for ten years in a closing system. The Division of Vocational Rehabilitation locates the person and suggests change that calls for the reframing of psychological, geographical, socialogical, and educational situations. Then it takes six months to a year to obtain self-transportation, attendant care, other equipment, etc. to pursue this new endeavor. Also, they find out that there are architectual barriers which hinder this changing process. Because this change takes so long and the disabled person is often-times isolated from the decision making process, the person is still in a closing system.

The Rehabilitation Act of 1973 with Sections 503 and 504 allows the disabled the opportunity to reframe their situations; that is, moving away from isolation to assimilation. It gives the disabled their equal rights by the elimination of attitudinal and architectural barriers. Transitional housing, Centers for Independent Living, have become a reality. With the idea of getting out of the institutions or the family basements into homes and jobs, illustrates a prime example of changing from isolation to assimilation. To reframe means to change the conceptual and/or emotional setting or viewpoint in relation to which a situation is experienced and to place it in another frame which fits the "facts" (the initial disability) of the same concrete situation equally well or

even better, and thereby changes its entire meaning.[17]

What makes reframing such an effective tool of change is that once the disabled individual and significant others perceive the alternative opening system (assimilation), they cannot easily go back to the trap and the anquish of a former view of "reality" (isolation).[18] Once the disabled have witnessed the mainstreaming of education, professional, and social opportunities, isolation is no longer a viable solution. These new psychological, cultural, social, and physical contexts brought about by reframing will seem confusing for the disabled. However, confusion is an important element of positive change in problem resolution alternatives.

Spontaneous, creative, and imaginative changes in the disabled individual's behavior-patterns evoke a new challenge to life; therefore, opening up the system. The activities for severely disabled individuals have grown over the years--wheelchair basketball, wheelchair olympics, swimming, boating, and other recreational opportunities. Also, educational and professional opportunities have greatly improved. These new-found opportunities evolved mainly out of second-order change in problem solving. Many disabled individuals and their significant others (especially health professionals, counselors, and advisors) have yet to fully understand second-order change. Many of the decisions regarding the disabled person have been first-order changes.

First-order change always appears to be based on common sense. This common sense approach is never spontaneous: "Wait until tomorrow;" "They have no ramps;" "Swimming is dangerous;" "You won't be able to keep up with your peers in school;" "If I go to the store or the movies, I will be stared at;" "Quadriplegics can't drive." These are examples of first-order change that create isolation and a more closing system.

Second-order change usually appears weird, unexpected, and uncommonsensical: "Let's go to a movie;" "We can adapt the airplane with hand controls;" "A blind individual can be a doctor or lawyer;" "I'd like to be a truck driver or even an auto mechanic." There is a puzzling, paradoxical element in the process of change. Applying second-order change techniques to the solution means that the situation is dealt with in the here and now manner. These techniques deal with effects and not with their presumed causes. The crucial question is what and not why. The use of second-order change techniques lifts the situation out of the paradox-producing trap created by the self-reflexiveness of the attempted solution and places it in a different frame.[19]

The birth of a child with a disability may result in a shift from anticipation, joy, and pleasant challenge to fear, apprehension, depression, and despair. Parents, who have realistic self-esteem and have developed a marital relationship based on the "open" system model, seem most adequately prepared to cope with entry of a child into their relationship, whether the child is normal and healthy or has a disability. This is also true if one of the partners in a relationship becomes disabled.

Disability frequently presents an immediate threat to the hopes, dreams, and aspirations of significant others. Suddenly, they must seek a new constellation of societal systems that will facilitate the growth and development of their disabled child. Just as the hopes, dreams, and aspirations of parents can be crushed with the birth of a disabled child, so can the hopes, dreams, and aspirations of the partners in a relationship be crushed when one of the partners in the relationship becomes disabled due to an accident or illness. The systems usually available may not prove useful, or may preclude service, because of the disabled individual's unique needs. High-risk factors are involved in this quest,

and unless careful planning occurs, the process can lead to further pain and sorrow.

Those involved with disability need to be aware of the importance of careful planning, but there is a danger of a paradox occurring. "I want you to want to be independent." The more significant others want this independency the less likely it will occur. That is why second-order change is so important. All the changes brought on by confusion, spontaneity, and imagination can be called life's little character builders.

Whether disability is brought on by an accident, illness, or a birth defect, there is going to be a strain on the relationships between the disabled and those closely associated with him/her. Valuable information can be gained from these relationships in terms of positive and negative feedback. Feedback in human communication systems is the response of a receiver to a message produced by the person who began the communication process. Once the process is started, all communicators are responding to each other, so it might be possible to suggest that all messages (except for the first message) are feedback for someone. It is important to understand that feedback from one communicator to another is regulatory behavior engaged in by one communicator, which controls the behavior of another. Regulation and control are basic to the survival of any system and a communicator system cannot survive without feedback.

The question of who is controlling and regulating the system is creating a healthy instability in the systems of disabled and their significant others. The instability means energy to the system; therefore, greater information sharing creating a more symmetrical relationship.

A symmetrical relationship is one where two people interchange the same type of behavior. They tend to criticize, offer advice, and initiate action.

Their behavior tends to be competitive and equal in nature.[20] In a complementary relationship the people involved exchange different types of behavior. One person may be a giver; the other, a receiver. One person may teach; the other, learns. One is the advisor; the other, the advisee. The people involved interchange behavior which complements, or fits together. To better understand the complementary relationship, there is a superior "one-up" position and a secondary "one-down" position.[21]

Feedback comes in either positive or negative form. Negative feedback characterizes homeostasis, or a steady state, that brings on a decrease in the output of deviation from a set of norms (standard behavior). On the other hand, positive feedback leads to change (the loss of stability or equilibrium) and brings about amplification of output deviation from the norm. For many years the disabled were asking questions about their sexuality and because the health professionals were ignorant or prudish or embarrassed, they gave negative feedback and the disabled accepted this. "Sex and marriage (for the disabled) don't mix." "Disabled men are unsuitable parents." This led to, or resulted from, complementary relations between advisors or counselors and the disabled. When the disabled responds in a way that might imply, "I know as much about this as you do," the nature of the relationship is put in question. The individual in the power position either has to redefine the relationship as complementary or accept the disabled's move towards symmetry.[22]

Many messages given off by assertive disabled individuals are placing complementary relationships in question. These messages can be considered a symmetrical maneuver. These maneuvers create instability in the relationship bringing about more equality. A good indication of more symmetrical relationships is the involvement of the disabled in decision-making procedures.

Disabled individuals make up more than 60 percent of consumer advisory groups, independent living programs, etc. The positive feedback from the disabled is coming in the form of suggestions, requests and commands. This is making the health professional feel somewhat uneasy because, as pointed out earlier, positive feedback causes change. Able-bodied individuals and health professionals are starting to see that the disabled are bringing more to the relationship than their dependency.

The development of a progressive opening communication system is an essential ingredient for successful mainstreaming of disabled individuals into society. It is a complex phenomenon, requiring understanding and practice--a system all people need to continually strengthen. When communication is open, forthright, and congruent, lives can become more enriched and meaningful. Though not an easy task, it does hold the potential for "unlocking the doors of development" in the quest of life.

Footnotes

Kenneth F. Sweet is an Assistant Professor of Communication in the Theater and Communication Department at the University of New Hampshire.

[1] Judy Heuman on a program called "Our Largest Minority: The Disabled" carried on Channel 6 (WCSH), NBC, January 11, 1981.

[2] Paul Watzlawick, Janet Helmick Beavin, and Don D. Jackson. Pragmatics of Human Communication: A Study of Interactional Patterns, Pathologies, and Paradoxes. (New York: W.W. Norton and Company, Inc., 1967), p. 119.

[3] A.I. Hall and R.E. Fagen. "Definition of System," General Systems Yearbook. 1:18-26, 1956. p. 18.

[4] Ibid.

[5] Watzlawick, Beavin, and Jackson, p. 121.

[6] Hall and Fagen, p. 20.

[7] Philip C. Chinn, Joyce Winn, and Robert H. Walters. Two-Way Talking with Parents of Special Children: A Process of Positive Communication. (Saint Louis: The C.V. Mosby Company, 1978), p. 93.

[8] Ibid.

[9] Barry Corbet. Options: Spinal Injury and the Future. (Denver: A.B. Hirschfeld Press, 1980), p. 60.

[10] Ibid., p. 117.

[11] Ibid., pp. 12-13.

[12] Ibid., p. 13.

[13] Watzlawick, Beavin, and Jackson, p. 188.

[14] Ibid., p. 199.

[15] Corbet, p. 15.

[16] Ibid.

[17] Paul Watzlawick, John Weakland, and Fisch. Change Principles of Problem Formation and Problem Resolution. (New York: W.W. Norton and Company, Inc., 1974), p. 95.

[18] Ibid., p. 99.

[19] Ibid., p. 83.

[20] Jay Haley. Strategies of Psychotherapy. (New York: Grune and Stratton, 1963), p. 11.

[21] Ibid.

[22] Haley, p. 13.